NEEDS ASSESSMENT
REQUIREMENTS FOR THE APPLICATION [Section 505]

Needs Assessment of the Maternal and Child Health Population

Needs Assessment Process

The California needs assessment has involved a two-year process conducted both within the Title V agency and, externally, in collaboration with local health departments, other State agencies and programs, health care providers, community groups, health care consumers and families. The methodology adopted for the development of the 2001-2005 needs assessment included the following major processes:

- Data collection and quantitative analysis of the trends in health status and health care access indicators, and programmatic data on direct health care services to the populations served by Title V.

A comprehensive review of the health status of women, infants, children, adolescents, and CSHCN was conducted. This included an assessment of the magnitude of specific health problems or measures of access to care and an analysis of recent and projected trends in the relevant measures. Data sources from various California government departments, academic institutions, federal agencies, and health care programs and providers were analyzed by State Title V staff in collaboration with other agencies. The review process highlighted those health needs for which significant progress has been achieved as well as those areas where annual objectives were not met. The process also uncovered new areas requiring further evaluation and possible intervention.

- Collaboration with county-level agencies in the preparation and review of local needs assessments and plans.

The California Title V agency facilitated a process whereby the local health jurisdiction in each of California's 58 counties and the three municipalities with health departments prepared a community health assessment and MCH plan. This process was noteworthy for the extensive coordination between State and local activities as part of the Title V assessment. The health jurisdictions worked with a broad range of local stakeholders, which included community and advocacy groups and health care providers, in conducting their assessments and defining the local priorities. At the end of the process, each jurisdiction developed a plan that included objectives and a scope of work upon which to base future program planning and development. To further support the statewide needs assessment, local agencies providing direct health care services to children and working with CSHCN were surveyed by CMS to identify areas of major unmet health care needs.

- Collaboration with a broad base of stakeholders throughout the state in the identification of priority issues and recommended intervention strategies.

Interviews were conducted by CMS with external stakeholders representing children's hospitals, physicians, academic institutions, medical professional organizations, and parent representatives to incorporate multiple perspectives on current issues and problems in the delivery of health services to Title V populations. Individuals serving as liaisons between the Title V agency and other government programs were also interviewed to provide insight into issues of coordination between programs such as Healthy Families and service delivery to CSHCN. Information was gathered from a survey of health care providers, carried out by CMS for a specific health program, and from a parent directed survey, conducted by a parent group for CSHCN (Family Voices). Reports based on information gathered by other agencies were also used, such as the May 2000 California Senate Office of Research Report on California's system for caring for CSHCN and the April 1999 California State Auditor's report on protecting California's children from lead poisoning.

A Title V planning meeting was attended by over fifty representatives of local health jurisdictions, legislative staff, the Department of Finance, the Health and Human Services Agency, other State and Federal agencies, community and private agencies, consumers, advocacy organizations, professional organizations, and academic institutions. The main purposes of the meeting were to draw on the knowledge and experience of the group to identify the needs of the Title V populations and potential resources to meet these needs. As background to these discussions, MCH and CMS staff reviewed health performance and outcome measures and trends for mothers, infants, children, and CSHCN. Proposed new Federal Health Status Indicators were also presented.

- Participation in strategic planning with other organizations to address critical needs of the Title V population.

The Title V agency participated in the development of the adolescent health strategic plan, the Dental Health Initiative, the school health plan, the health care program for children in foster care, and the children's asthma program. Participation in these planning processes provided an in-depth understanding of the extent of child and adolescent health needs in California. The MCH Branch supported the preparation of the Adolescent Health Strategic Plan, "Investing in Adolescent Health: A Social Imperative for California's Future", as part of an effort to establish a consensus and develop and implement policies that support adolescent health. The MCH Branch also participated as an active member of the CDHI Advisory Committee which developed the policy recommendations for the oral health plan, The Oral Health of California's Children: Halting a Neglected Epidemic". The Department of Health Services and the Department of Education developed the School Health Report, as part of a joint effort to further the development of the infrastructure needed for coordinated school health activities. The CMS Branch worked with the Department of Social Services to develop a program that utilizes public health nurses to oversee health care services for children in foster care and with the Chronic Disease Branch to develop the new asthma program that will increase awareness about asthma and early intervention for young children.

- Public input and document review

The FY2001 preliminary report and application was circulated to encourage broad-based input in planning for the next five years. Input relating to the new needs assessment was also solicited by CMS at the time of circulation of the FFY 2000 report and application.

The main strengths of the needs assessment process include the involvement of a broad range of stakeholders and the reliance on a combination of quantitative and qualitative analytic methodologies to validate the significance of the health needs of the Title V population. An additional strength was the vital role of the local health departments, in collaboration with local representatives, in the identification of local needs and the preparation of local needs assessments. Their ongoing participation increased the input from the representatives of local agencies and community groups.

Limitations of the needs assessment process must also be acknowledged. Given the size and diversity of California, the Title V agency faces a challenge in representing the needs of the diverse population groups who are Title V stakeholders. While statewide data include all populations, and efforts have been made to invite consumer input, not all population groups have actively participated in the process. A further limitation of the quantitative review relates to some reliance on data files collected for administrative purposes.

Needs Assessment Content

Overview of the Maternal and Child Health Population's Health Status

The information presented in the following sections contributed to the identification of the Title V priorities. The health status of California's population of pregnant women, mothers, infants, children, and CSHCN is analyzed in terms of the major indicators of mortality and morbidity and the prevalence of selected risk factors. Health status is described in the overview in relation to the specific Title V populations. Health care access is assessed in relation to measures of insurance coverage and utilization of preventive, primary, and specialty care services. Issues of access are described under the appropriate level of the pyramid and in reference to the specific Title V population. Where data are relevant to specific Federal and State Performance (FPM and SPM), Outcome Measures (FOM and SOM), and Core and Developmental Health Status Indicators (HSI and DHSI), the measure is noted.

- Health Status of Pregnant Women, Mothers, Infants

<u>Infant Mortality</u>

One indicator of the progress achieved in improving the health status of California's infants is the reduction of deaths during infancy. California's infant mortality rate (IMR) (FOM 1) in 1998 was 5.7 deaths per 1,000 live births. The IMR declined by one-third from 1989-98, falling from 8.5 to 5.7 deaths per 1,000 live births. The Healthy People 2000 Objective of 7.0 deaths per 1,000 live births has been achieved and the state is well

on its way toward meeting the Healthy People 2010 Objective of 4.5 deaths per 1,000 live births.

California's neonatal mortality rate (FOM 3) in 1998 was 3.8 deaths during the first 28 days of life per 1,000 live births. The state's overall neonatal mortality rate has decreased by 27 percent, from 5.2 per 1,000 live births in 1989 to 3.8 per 1,000 in 1998. California has achieved the Healthy People 2000 objective of 4.5 deaths per 1,000 live births and is making progress toward the Healthy People 2010 Objective of 2.9 neonatal deaths per 1,000 live births.

In 1998, California's postneonatal mortality rate (FOM 4) was 1.9 deaths among infants 28-364 days old per 1,000 live births. The postneonatal mortality rate decreased from 3.3 per 1,000 live births in 1989 to 1.9 per thousand live births in 1998, representing a 42 percent decline. The 1998 rate is below the 2.5 postneonatal deaths per 1,000 live births set as the Healthy People 2000 Objective. The relevant 2010 Objective is 1.5 postneonatal deaths per 1,000 live births. California's perinatal mortality rate (FOM 5) was 8.9 deaths per 1,000 live births and fetal deaths in 1998, having declined by 18 percent from 10.8 in 1989. Perinatal mortality measures neonatal deaths under seven days and fetal deaths of at least 20 weeks of gestation. Differences in the definition of the measure preclude comparison with the Healthy People objectives.

Low Birthweight

The percent of California's live born infants who were low birthweight (LBW), less than 2,500 grams (HSI 4A), was 6.2 percent in 1998. This figure was higher than the Healthy People 2000 and 2010 Objective of 5.0 percent. The percent of low birthweight infants increased slightly from 6.1 percent in 1989 to 6.2 percent in 1998. While this upward trend over time was statistically significant, when the analysis is restricted to LBW among singleton births (HSI 4B), no increasing trend is observed. The percent of LBW among singletons remained at 4.9 percent from 1996-98. Since the increase in multiple births associated with the use of reproductive technologies is likely to affect the percent of LBW infants, stratification by plurality is appropriate in analyzing the LBW problem and developing appropriate interventions. Reducing the LBW rate remains one of the major challenges for the state. Further identification of the causes of preterm births can contribute to achieving this goal. In 1998, 1.2 percent of live born infants were very low birthweight (VLBW) (HSI 5 A). The percent increased from 1.1 percent in 1989. A modest but statistically significant upward trend was observed from 1989-98. As noted in relation to the percent of LBW newborns, when the analysis is restricted to VLBW among singletons, the time trend is no longer statistically significant. The percent of VLBW among live-born singletons has remained at 0.9 percent from 1994 to 1998.

Racial and Ethnic Disparities

The notable progress achieved in the overall reduction of infant deaths does not diminish the importance of the persistent racial and ethnic disparities (FOM 2) in perinatal health status. Of greatest concern is the marked disparity in risk among African-American

newborns. In 1998, 13.7 black infants died in their first year of life for every 1,000 live births. The comparable figure for white infants was 5.1 deaths per 1,000 live births. While the IMR is falling among black as well as white infants, the gap has not narrowed**.** From 1989-98, the ratio of the black/white IMR did not exhibit any statistically significant trend.

The 1998 neonatal, postneonatal, and perinatal mortality rates for African American infants were between two and three times the corresponding rates for whites. The percent of low birth infants was also twice as high among African American newborns (11.7 percent) compared with the percent among white infants (5.8 percent). California's Black Infant Health Program and the SIDS program are designed to address the needs of pregnant black women and their newborns to improve perinatal health status.

Racial and ethnic disparities in infant health status are observed in relation to a number of health problems in addition to infant mortality. Examples include the higher rate of neural tube defects among Latina women and the teen birth rate among African American and Latina adolescents. These disparities are discussed below in relation to the specific problem.

Teen Pregnancy

California has achieved a significant decline in the birth rate among females aged 15 to 17 years old (FPM6). Increasing awareness of the risks associated with sexual activity, an increased State investment in pregnancy prevention programs for teens, greater availability of contraceptives, and more aggressive enforcement of statutory rape may have contributed to this decline. In 1998, the rate of births was 32.6 per 1,000 15-17 year-olds. The rate fell by 30 percent from a high of 46.5 births per 1,000 in 1991. Despite this notable progress, in 1998, there were 21,630 births to 15-17 year-olds.

Racial and ethnic disparities in the teen birth rate persist despite the marked declines that have occurred across racial and ethnic groups in recent years. Compared with the 1998 rate of 13.0 teen births per 1,000 teens aged 15-17 years among white non-Latina adolescents, the rate among Latina adolescents was 61.9 per 1,000, and among African American teens, 41.4 per 1,000. The continued reduction of the teen birth rate among all population groups remains a priority for California's Department of Health Services and the Title V agency.

Breastfeeding

The low prevalence of exclusive post-partum breastfeeding (FPM 9) in California despite the immunological, nutritional, and psychological benefits breastfeeding provides the infant and mother, highlights the importance of this issue. In 1998, 43.5 percent of mothers with a live birth in California intended to exclusively breastfeed at hospital discharge. The 1999 Maternal and Infant Health Assessment (MIHA), a survey of women who delivered live born infants in California in 1999, provides information on breastfeeding rates that include exclusive and mixed feeding. According to the 1999

MIHA, when exclusive breastfeeding and mixed feeding are combined, 87.5 percent of the women who delivered a live-born infant in the state in 1999 breastfed after delivery, and 58.8 percent continued to breastfeed when the infant was two months old. MIHA data will be analyzed to identify populations at risk for failure to initiate breastfeeding, early adoption of mixed feeding practices, and early breastfeeding cessation. The survey will also be used to gain a better understanding of the reasons for these practices. Over the last five years, California has implemented a breastfeeding initiative to increase the breastfeeding rate through heightened public awareness and education, changing hospital practices, and increased collaboration among breastfeeding advocates.

AIDS

Women continue to be the fastest growing population with AIDS in California. As of January 1, 1998, there were a total of 7,367 AIDS cases among women 25-44 years of age, and 553 cases among children less than 13 years of age. It is estimated that in 1996 there were 9,300 to 12,900 women living with HIV/AIDS in California. AIDS affects women and children of color disproportionately. Among women, African Americans had the highest percentage, 36.9 percent of all cases reported, followed by whites, 36.2 percent and Latinas, 23.6 percent. African American children had the highest rate of pediatric AIDS (3.06 cases per 100,000 population per year, 1988-97)[25]. The most frequent source of infection for children was from perinatal transmission from the mother. The mother's infection was most often from injection drug use or through heterosexual exposure to an injection drug user. Three local health jurisdictions identified the reduction of HIV infection in women of childbearing age as a priority for their MCH programs. The majority of local Perinatal Service Coordinators are working with perinatal health care providers and their staff to assist women in receiving appropriate HIV information and screening tests during the prenatal period.

Birth Defects

The prevention of birth defects as well as screening and early intervention for children who are born with these conditions can prevent disability and child mortality. Based on registry data that covers eleven counties representing half of the state's births, the rate of neural tube defects (NTDs) in California declined from 8.0 per 10,000 live births plus fetal deaths in 1990 to 5.3 in 1997 (SPM 6). Of particular concern is the fact that the risk for NTDs is more than twice as high among infants of Mexican-born mothers and fathers when compared with infants of white mothers and fathers. A heightened risk has not been observed among infants of U.S.-born parents of Mexican descent[27]. Further research is needed to identify the causes of this disparity. Current estimates suggest that approximately 50 percent of pregnancies affected with NTDs could be prevented with adequate consumption of folic acid from one month before conception through the first three months of pregnancy[27]. According to the 1999 MIHA results, only 26.5 percent of women who delivered a live born infant in the state in 1999 took multivitamins or folic acid on a daily basis just before they became pregnant. Approximately one fourth of the women did not take multivitamins or folic acid on a daily basis after learning of their pregnancy. The MCH and Genetic Disease Branches promote increased consumption of

folic acid among women of childbearing age and disseminate the findings of the registries to local MCH programs. MCH programs such as the Adolescent Family Life Program (AFLP) and the California Diabetes and Pregnancy Program (CDAPP) have integrated messages about the importance of folic acid consumption in their health education.

Domestic Violence

Domestic violence is a major public health problem affecting a large number of women and their families. Domestic violence is the leading cause of injury to women ages 15-44 in the U.S. In California, 196,832 incidents of domestic violence were reported to law enforcement, and 56,892 domestic violence arrests were made in 1998. The 1998 California Women's Health Survey (CWHS) provides information on the prevalence of intimate partner physical abuse, with the severity ranging from being pushed to being threatened with a gun or knife. The 1998 CWHS findings indicate that approximately 6.0 percent of the women over 18 in California reported being victims of intimate partner physical domestic violence (IPP-DV) during the past 12 months (proposed SPM 8). Younger women were more likely to report being victims of IPP-DV than older women. Approximately 71 percent of IPP-DV victims have children younger than 18 at home; 42.9 percent have children aged 1-5 in their households. MCH supports domestic violence shelters and a wide range of enabling services for victims in addition to numerous prevention programs, including those that address teen relationship abuse assessment and training.

Substance Abuse

Alcohol and illicit drug use present significant threats to the health of the mother, infant, and child. While recent statewide data on the severity of the problem of perinatal substance abuse are not available, data from the 1999 California MIHA indicate that approximately 20 percent of mothers whose infants were born in the state reported having consumed alcohol, and 11.5 percent reported smoking during their most recent pregnancy**.** Further progress is needed to reach the Healthy People 2010 Objectives of six percent of pregnant women consuming alcohol and two percent smoking. Information from local agencies and hospitals suggests that trends in illicit substance use among pregnant women are more difficult to monitor because users are better able to avoid hospital-based testing. Case studies from FIMR show that perinatal substance abuse is related to instances of failure to thrive and child neglect. Consequently, the problem has been highlighted by the inclusion of perinatal substance abuse as a program priority for the three federally-funded Healthy Start programs, and in California, many county needs assessments identified substance abuse as a local priority.

Maternal Mortality

Maternal deaths have devastating long-term effects on the children and families of the deceased. Maternal deaths should be considered sentinel events; for every woman who dies of maternal complications, many more experience serious complications of pregnancy and are hospitalized for conditions related to pregnancy. The maternal

mortality rate (SOM 1), the number of pregnancy-related deaths, declined in 1998 to 6.5 maternal deaths per 100,000 live births from 8.6 in 1997. The maternal mortality rate has fluctuated considerably from 1989-98. Random fluctuation is not uncommon when measuring rare events such as maternal deaths.

The Regional Perinatal Programs, FIMR, and other Title V programs will continue to improve access to the level of prenatal and delivery services appropriate to each woman's needs. Incorporation of maternal mortality case reviews in the Los Angeles FIMR project in 1996 provided valuable information on the risk factors and services needed to reduce maternal death[28]. More recently, the MCH Branch has begun to work collaboratively with the UCLA School of Public Health, to develop a set of maternal quality of care indicators in order to address the high rate of complications during pregnancy and the problem of maternal mortality.

- Health Status of Children and Adolescents

Childhood Mortality

Childhood mortality rates provide critical indicators of the health status of California's children and youth as well as the overall effectiveness of relevant public health interventions. From 1990 to 1998, the leading causes of death among children aged 1 to 14 years were injuries (regardless of intent), congenital anomalies, and malignant neoplasms. When the age group is restricted to the 5-14 year-olds, homicides replace congenital anomalies as a leading cause of mortality. The rate of mortality among children aged 1 to 14 years (FOM 6) in California decreased by more than one-third from 1990-98, declining from 30.3 to 18.9 deaths per 100,000 children. Reductions in the rate of injury-related mortality, as described below, have contributed to this achievement.

Racial and Ethnic Disparities

Racial and ethnic disparities are observed in relation to a number of measures of child health status. In 1998, the child mortality rate among African Americans, 34.1 deaths per 100,000 children aged 1-14 years, was approximately twice as high as the rate among white children, 16.5 deaths per 100,000. The adolescent homicide death rate also reveals significant racial and ethnic disparities. In 1998, the homicide death rate per 100,000 adolescents aged 15- 19 years was over nine times greater among African Americans, 48.2 homicide deaths per 100,000, when compared with whites, 4.9 deaths per 100,000. A heightened risk of mortality from homicide was also observed among Latino and Asian and Pacific Islander adolescents compared with whites.

Adolescent suicide death rates also reveal racial and ethnic disparities. In 1998, the suicide death rate was approximately 45 percent higher among white teens at 7.8 suicide deaths among teens aged 15 through 19 years, compared with Latino adolescents, for whom the rate was 5.4 suicide deaths per 100,000.

Childhood Injury Deaths

Public health interventions to reduce injury-related child deaths can have a major impact on lowering the child mortality rate. The death rate resulting from unintentional injuries among children 1-14 years of age (DHSI 1A) was 6.2 per 100,000 in 1998. This represents a nearly 50 percent decline from the 12.1 rate in 1990. Despite this considerable decline, injuries remain the leading cause of death among children 1-14 years of age.

Motor vehicle crashes are the leading cause of death among California's children and youth 1-19 years of age. A large portion of motor vehicle-related deaths is preventable. Among younger children, the failure to use proper child restraints is a major contributing factor. Among both children and adolescents, alcohol consumption by the driver is another cause of motor vehicle accident deaths. An additional risk for adolescents is the lack of driving experience. In 1998, the California motor vehicle fatality rate was 2.8 deaths per 100,000 children 0-14 years of age (FPM 8), having declined by nearly 50 percent since 1990 when the rate was 5.4. Among adolescents 15 through 19 years old, the 1998 motor vehicle death rate was 17.2 deaths per 100,000 adolescents (SPM 5), 37 percent below the 1990 rate, 27.3 percent. Despite this progress, over 600 infants and youth from 0-20 years of age lost their lives in motor vehicle-related accidents in 1998.

When the younger age group of 1-4 year olds is examined separately, drowning is the leading cause of death in California (SPM 3). Bathtubs, swimming pools, and spas pose a special threat to young children. Children who survive near drowning often have severe brain damage, requiring permanent hospitalization in state-operated developmental centers. Drowning deaths and permanent brain damage from near drowning to children can be reduced through appropriate public health action. The rate of swimming pool related drowning deaths among children aged 1 through 4 years decreased from 3.3 deaths per 100,000 in 1990 to 2.1 in 1998. There has been a significant downward trend over that period.

Homicide

Homicide is the second leading cause of death among California's teenagers, aged 15 through 19 years. It is the leading cause of death among adolescent African Americans and Latinos. While it is illegal for minors to buy guns, firearms are obtained from older friends, unknowing parents, and illicit street sales. Societal acceptance of the portrayal of gun violence in the media and popular entertainment may contribute to youths' perception of gun violence as one way of resolving conflict and personal frustrations. In California, significant gains have been achieved in reducing the adolescent homicide rate (SPM 4) from 25.7 deaths per 100,000 youth 15 through19 years old in 1990 to 17.1 in 1998. Despite these gains, there were 386 homicide deaths among 15 through 19 year olds in 1998.

Suicide

Suicide is the third leading cause of death among adolescents and young adults in California. Life's transition from teenager to adult can be extremely stressful because of peer pressure and problems of self-esteem. Many teens experience significant changes beyond their control, such as divorce of their parents and relocation to a new community. Biological factors also contribute to the mood disorders that are associated with adolescent suicide. Substance abuse can also play a role in the problem of adolescent suicide. In California, the 1998 suicide rate was 6.3 deaths per 100,000 youths aged 15 to19 years (FPM 16). This represents a 32 percent decline from the rate of 9.2 in 1990, and a statistically significant declining trend.

Youth Smoking

California has made progress in reducing the prevalence of adult smoking while youth smoking prevalence has remained relatively stable since 1994. In 1998, 10.7 percent of 12-17 year-olds reported having smoked at least one cigarette in the past 30 days. Racial and ethnic differences have been observed in the prevalence of youth smoking. Whites have had the highest rates, followed by Hispanics, Asians, and African Americans. Some differences by age group have been observed. Since 1994, the smoking prevalence in the 14-15 and 16-17 age groups has declined; the prevalence has increased in the 12-13 age group. The State has restricted cigarette advertising that is targeted to youth by limiting the sites where advertisements may be located, increased enforcement of laws that prohibit the sale of tobacco products to youth, and the implementation of a nationally regarded public education campaigns designed to reach children and adolescents. The campaigns utilize the advertising and marketing strategies of the tobacco sellers. Maintaining the focus on tobacco prevention among youth is necessary to counter the impact of tobacco advertising. The imposition of the surtax on cigarettes resulting from the passage of Proposition 10 should have a significant impact on reducing youth smoking.

Alcohol and Illicit Drug Use

Data from the 1997-98 California Student Substance Abuse Survey indicate that alcohol is the most popular drug among California's youth. Approximately 47 percent of students in 11th grade and 22 percent of those in 7th grade reported drinking alcohol in the past thirty days. Binge drinking, the consumption of five drinks in a row, in the past two weeks, was reported by 10 percent of the 7th graders and 26 percent of 11th graders[29]. Alcohol is the most common co-factor in motor vehicle accidents and injuries. The inappropriate use of alcohol by youth is associated with risk-taking behavior and poor school performance.

Illicit drugs also pose significant health risks to the adolescent population. The California Student Substance Abuse Survey of 1997-98 data indicate that 11 percent of 7th graders reported use of marijuana in the past six months. That figure rose to 33 percent among 9th graders, and 42 percent among 11th graders. The ready availability of alcohol and illicit drugs among adolescents influences their use and adult attitudes toward youth drug

use range from permissive to punitive. Programs and services for youth involved in drug use are unavailable in many areas.

Overweight and Obesity

The prevalence of overweight in California's children is higher than the national average and is increasing annually. Sedentary activity, as measured by hours of television viewing, is also increasing**.** Among low-income children served in the Child Health and Disability Prevention Program (CHDP), 14.1 percent had weights for height above the 95th percentile (SPM 10). The health risks of overweight in children include the probability that the weight problem will continue into adulthood and earlier onset and more severe forms of a variety of chronic diseases such as high blood pressure, Type II diabetes, stroke and heart disease. In today's environment of convenience and readily available low-cost foods of high caloric density, it is likely that the problem of overweight among children will increase unless concerted efforts are made to reverse this trend through the creation of an environment that supports a healthy lifestyle.

Need for Health Referrals

In 1997-98, approximately 2.3 million children and adolescents received services through the CHDP program. CHDP serves children from families with incomes up to 200 percent of the Federal Poverty Level (FPL) and provides basic health assessments as well as screenings for problems in dental health, nutrition, development, vision and hearing. If problems are suspected, referrals are made for further diagnosis and treatment. The number of referrals made indicates the number of children for whom concerns about health status were raised. In 1997-98, of the children who were screened, 21.9 percent required referral for diagnosis and/or treatment for medical issues, 6.9 percent for dental and oral problems, 5.0 percent for vision, and 1.4 percent for hearing. Nutritional issues, including both over and underweight, led to a referral in 2.0 percent of children who were screened.

- Health Status of Children with Special Health Care Needs

Number of Children Receiving CCS Services

CCS authorizes medical services and provides case management for children with most of the serious medical conditions of a physical nature that can be cured, improved or stabilized. To be eligible for these CCS services, a child must be from a family with an annual income of $40,000 or less, or the annual cost for medical care must be estimated to exceed 20 percent of family income. From 1997 to 1999, the number of children enrolled in the CCS program rose by 14 percent, to an active CCS caseload of 140,129.

Diagnoses of CSHCN

The major diagnostic categories of children in the CSHCN program, in FY 1994 through 1998, indicate that 24 percent had congenital anomalies and 17 percent had other

perinatal conditions. Diseases of the nervous system were noted in 20 percent of the children and, of these, 31 percent had hearing loss.

If undetected, hearing deficits can interfere with language and neurologic development. To increase detection of congenital hearing deficits, CMS is instituting hearing screening (FPM 10) for all infants born in CCS approved hospitals. The number of infants and young children in the CCS program with detected hearing loss is therefore expected to increase markedly over the next two years.

Referral for specialty medical treatment of children with the sentinel conditions of spina bifida, cleft palate and acute lymphoblastic or lymphocytic leukemia (ALL) (SPM 2) is one of the indicators CCS has been using to assess the care received by CSHCN. Of note, the percent of children in the CCS case management data system with these diagnoses has been declining over the past three years, from 6.4 percent in FY 1997 to 4.9 percent in FY 1998 and 3.6 percent in FY 1999. Small decreases in the percent of children with each of the diagnoses have contributed to this aggregate drop. (Spina bifida is a neural tube defect, SPM 6.)

While over 500 children in California are currently thought to be infected with HIV, only 86 children in the CCS program were identified has having HIV infection in the 1998-99 open case files. HIV infected children are eligible to receive services through CCS but many receive care through other programs (such as Ryan White) and there may also be some undercounting in the case files due to listing of these children under alternative diagnoses. Through the HIV Children's Program, CCS assures that HIV infected children are identified and appropriately referred for health services.

The California newborn genetic screening program detects inborn errors of metabolism, endocrine disorders and hemoglobinopathies (FPM 4). All are eligible conditions for the CCS program. However, the number of California children found to actually have these disorders is small. In 1998, the number of confirmed cases (out of 522,653 occurrent births) was: 13 children with phenylketonuria; 200 with primary congenital hypothyroidism; 7 with classical galactosemia; and 107 with sickle cell disease.

Children Served by the Medical Therapy Program

The CCS Medical Therapy Program (MTP) provides physical and occupational therapy services to children with cerebral palsy and neuromuscular conditions, without regard to family income. The number of children requiring and using the MTP program has increased by 36 percent over the past nine years, from approximately 18,000 in 1990-91 to 24,500 in 1998-2000. Since the birth rate in California progressively fell over this time period and most children with qualifying conditions are referred to the MTP, the absolute number and relative proportion of children in the state with these conditions appear to be increasing.

VLBW Infants

VLBW infants (birthweight less than 1,500 grams) (FPM 15, HSI 5A and 5B) are at risk for a number of perinatal disorders and have a high neonatal mortality rate (NMR, birth up to 28 days). In 1995-97, the NMR for all California infants of 500-1,499 grams was 154.5 per 1,000 live births. The race specific NMR for this weight group was highest for non-Hispanic whites, at 159.8 per 1,000 live births, and intermediate for Hispanic infants, at 156.7 per 1,000 live births. Black infants of VLBW have a survival advantage and in 1995-97 had the lowest NMR, at 141.1 per 1,000 live births. The major neonatal disorders that lead to mortality in VLBW infants are CCS eligible conditions. CCS eligibility provides access to needed newborn intensive care services, with the goal of reducing the high mortality rate.

VLBW infants are also at risk for long term sequelae from perinatal disorders. From 1987 to 1993, infant mortality rates in California decreased for the smallest infants, those weighing 500-999 grams at birth. Infant mortality rates dropped from 718 to 583 per 1000 live births for infants weighing 500 to 749 grams at birth and from 375 to 203 per 1000 live births for infants weighing 750 to 999 grams. The survivors from this period are now children and young adolescents.

A 1997 study of 500-999 gram infants born during a concurrent period (1979-1991) and cared for in tertiary level, Northern California nurseries, found that only 61 percent of the survivors were completely normal, when assessed at a mean age of 55 months[30]. This 61 percent had no neurologic, neurosensory, or cognitive deficits. However, long-term abnormalities were noted in the other 39 percent, were associated with health problems they had experienced in infancy such as intracranial hemorrhage and chronic lung disease. A number of these extremely low birthweight survivors have conditions that make them eligible for the CCS program and MTP services.

Improving the long-term outcome of VLBW infants and other critically ill neonates is a major component of CCS responsibility. CCS activities include development of standards for delivery of newborn intensive care, approval of hospitals and intensive care nurseries, and infant outreach and follow-up programs.

Additional Sources of Information on CSHCN

Additional information on the health status of CSHCN in California is anticipated in the next two years, with the implementation of new survey tools. The Maternal and Child Health Bureau, in conjunction with the National Center for Health Statistics, is carrying out a national telephone survey which will include our state. Locally, a biannual California Health Interview Survey (CHIS) is being instituted, which will have questions about serious and chronic illness and physical limitations. Separate CHIS questionnaires are being developed for children and adolescents. The Medically Vulnerable Infant Program (MVIP), successor to the California High Risk Infant Program, will provide services to many of the infants discharged from newborn intensive care units. A data system, including monitoring of outcomes, is being integrated into the MVIP program.

Direct Health Care Services

- Access to Preventive and Primary Services for Pregnant Women, Mothers, and Infants

No direct health care services are provided for pregnant women or mothers, unless these individuals are young women who are also served by the CHDP and CCS programs. The CHDP program provides direct health care assessments and screening for infants, which includes six visits during the first year of life. These include a physical examination and evaluation of growth, developmental, nutritional, and dental status, as well as anticipatory guidance, sensory screening, testing for anemia, blood screening for lead poisoning, and administration of immunizations. In 1997-98, 550,596 infants under one year of age received health assessments through CHDP.

Though the CHDP program includes an initial health assessment visit during the first month of life, an issue raised during the needs assessment was the need for an additional, immediate postnatal visit, during the first few days after birth. Current hospital stays for delivery are short and infant health problems may not become apparent for several days. With increasing breastfeeding rates as a State goal, early guidance for breast feeding mothers, reassurance and assessment of infant nutritional status, are needed.

- Direct Health Care Services for Children and Adolescents

The CHDP program provides nine health assessment and preventive guidance visits for children over one year and up through 20 years of age. Two visits are provided in the second year of life, one visit each at two and three years of age, and one visit each at 4-5, 6-8, 9-12, 13-16, and 17-20 years. Health examinations and screenings are provided as described for infants and additional services, such as TB testing, pelvic examinations, and counseling on risk behaviors are included. In FY 1997-98, 1,735,101 children and adolescents received health services through CHDP. CHDP also fulfills the role of referring children to other programs for further diagnosis and treatment, when problems are identified.

When the CHDP program periodicity of visits was established it conformed to national standards. However, national recommendations have changed. The number of health assessment visits provided in the CHDP schedule for children over age three years and adolescents does not allow for annual health assessment visits, for children in the State-Only funded and Medi-Cal Fee-for-Service parts of the program. Annual examinations for children are currently recommended by national organizations (such as the American Academy of Pediatrics) and are required of health plans participating in the Medi-Cal Managed Care and Healthy Families programs. Increasing the periodicity of visits, so that they will be equivalent, for all children served by CHDP was raised during the needs assessment and is an important CMS goal.

- Direct Health Care Services for Children with Special Health Care Needs

The CCS program covers health care services, through approved providers, for almost all serious medical conditions of a physical nature, that can be cured, improved or stabilized. Conditions such as birth defects, chronic illness and physically handicapping conditions are medically eligible. The active case load of CSHCN in the CCS program was 140,129 in 1999. However, since individual children may enter or leave the case load, greater numbers of children may actually be served. New, CCS eligibility regulations, that made modifications in eligible conditions, were developed last year and were issued as emergency regulations. These regulations have now been incorporated in California code after revision based on public comment (Title 22, Section 41800-41872).

CCS provides direct health care services for children with a CCS eligible condition in the Medical Therapy Units (MTU). There are 104 MTU units and satellite units located throughout the state, which provide physical and occupational therapy to close to 25,000 children based on medical need. Therapy services are provided based on medical prescription and services are coordinated between family, therapists and medical providers through medical therapy conferences. In recent years, MTU services have become more complex, involving use of additional equipment and interventions. MTU sites are located at schools, in a child oriented environment, and the overall approach to provision of services involves interagency cooperation between CMS and the Departments of Education, Developmental Services and Social Services.

Though MTUs are dispersed and situated at sites that would be focal within a community, given the size of California and the number of children served, some CSHCN and their families need to travel over distance to reach their MTU. Provision of home based therapy services is constrained by the time that would be required for therapist travel, numbers and reimbursement costs of available therapists, and lack of portability of some services.

Enabling Services

- Access to Preventive and Primary Services for Pregnant Women, Mothers, and Infants

Prenatal Care

Expanded access to prenatal services is a long-standing priority in California. Through enabling services such as the provision of health insurance coverage, the State has eliminated most financial barriers for reproductive and prenatal services for low-income women and preventive and primary services for infants. In 1998, birth certificate files indicate that less than three percent of resident women who delivered a live-born infant in California had either no identified payer source for prenatal care or were self-payers[19].
In 1998, 82.4 percent of pregnant women who delivered in California obtained first trimester prenatal care (FPM 18); this represents a 13 percent increase from 1989 (72.6 percent). Progress has been achieved in narrowing the gap between white women and black and Latina women in relation to care initiation. While white women were over 35 percent more likely than Latina women to receive first trimester care in 1989, this figure

was reduced to 13 percent in 1998. Despite this progress, further efforts are needed to achieve the Healthy People 2010 Objective of 90 percent first trimester care.

Medi-Cal prenatal coverage is provided for full-scope prenatal, delivery, and postpartum medical services. All pregnant women with incomes below 200 percent of the FPL are Medi-Cal eligible. A property disregard program, a mail-in application, and presumptive Medi-Cal eligibility facilitate early and speedy enrollment. Previous access barriers have been removed thereby allowing low-income pregnant women who are ineligible for federal benefits to receive State-only prenatal care coverage through Medi-Cal.

In 1998, Medi-Cal covered the prenatal costs for 40 percent of the women who delivered a live-born infant in California. The gap between the Medi-Cal and non-Medi-Cal insured women in relation to the percent with first trimester care (HSI 6C) has narrowed significantly; the absolute difference between the two groups was reduced from 29 percentage points in 1989 to 15 percentage points in 1998.

Table 2: Prenatal Care Utilization Indicators by Type of Insurance

Indicator	Year	Type of Insurance: Medi-Cal (%)	Type of Insurance: Non-Medi-Cal (%)
First Trimester Care	1989	53.8	82.8
	1998	73.6	88.6
Adequate or Adequate Plus (Kotelchuk Index)	1989	45.7	65.7
	1998	68.9	78.9

Source: State of California, Department of Health Services, Vital Statistics, Center for Health Statistics, California Birth Certificate Master File, 1998.

Access to prenatal care is assessed in terms of the time of initiation and the frequency of visits in accordance with the Adequacy of Prenatal Care Utilization Index (Kotelchuck Index). In California, the percent of live born infants whose mothers' prenatal care use was adequate or adequate plus on the Kotelchuck Index increased from 60.2 percent in 1989 to 74.9 percent in 1998, an increase of approximately 25 percent (HSI 3). A comparison of the Kotelchuck Index for women on Medi-Cal and those not on Medi-Cal (HSI 6D) shows that the gap between the two groups was reduced from an absolute difference of twenty to ten percentage points between 1989 and 1998.

The Access for Infants and Mothers (AIM) Program provides state-subsidized third party insurance to uninsured pregnant women and infants with household incomes between 200-300 percent of the FPL. Annually, AIM serves approximately 4,000 moderate-income women[20]. The combination of Medi-Cal, AIM and private health insurance means that near universal health insurance coverage for prenatal and maternity care has been achieved in California.

Prenatal Care Outreach

Insuring early and continuous use of prenatal care services requires both an adequate infrastructure and effective population-based outreach. MCH Outreach and other programs like Baby CAL, AFLP, and Black Infant Health (BIH) provide outreach to pregnant women to encourage early enrollment in prenatal care. Efforts to improve access can also be strengthened by information that identifies problem locations. The provision of enhanced support services and program incentives can also improve prenatal care utilization. Population-based programs like the Comprehensive Perinatal Services Program (CPSP) and BIH offer such enhanced services.

Early and adequate prenatal care is particularly important for women whose pregnancies are complicated by medical conditions such as diabetes, hypertension, or other disorders. Scientific evidence demonstrates that many of the problems experienced by the mother and infant that are associated with diabetes, can be reduced or prevented with optimal prenatal care and diabetes control. To improve access to adequate prenatal care among women with special conditions, MCH supports such programs as the California Diabetes and Pregnancy Program (CDAPP).

Improvements in women's access to health care should extend through the intrapartum period to promote maternal and infant health. California created the Family Planning Access, Care and Treatment (Family P.A.C.T.) program in 1996. The program provides comprehensive family planning services for the many low-income men and women who are ineligible for Medi-Cal and have no other source of family planning coverage. Family P.A.C.T. makes available comprehensive family planning services, including contraceptive methods, screening for sexually transmitted infections, and breast and cervical cancer to all women and men in California with incomes at or below 200 percent of FPL. By December 1999, 1.9 million clients had been enrolled in the program, along with 2,764 provider entities. By improving the early diagnosis and treatment of sexually transmitted infections and reducing the number of unintended and/or unwanted pregnancies, Family P.A.C.T. is expected to make a significant contribution to the health status of the maternal and child population[22].

Cultural Competency

Access to care can be enhanced through programs that recognize the cultural diversity of the population. Given California's diverse population, the design of culturally appropriate programs represents a critical challenge. The California SIDS Program, in collaboration with the California Black Infant Health (BIH) Program, developed a SIDS Risk Reduction campaign designed specifically for the African-American community to help reduce the racial disparities in infant health. Similarly, breastfeeding and folic acid promotion materials have been designed to address cultural practices and beliefs among a number of the state's many ethnic communities. Several other prenatal programs for high-risk women also incorporate materials that are adapted to the cultural norms of the client populations.

Infant Health Screening and Assessment

The CHDP program provides health services to Medi-Cal eligible children and other low-income children not eligible for Medi-Cal. In 1997-98, CHDP health assessments and screenings were carried out in 352,914 infants (up to 1 year of age) enrolled in Medi-Cal, or 84.5 percent of the total Medi-Cal infant population (HSI 2A). An additional 197,682 infants covered by State funding sources also received CHDP health and screening services.

- Access to Preventive and Primary Services among Children

Child Preventive Assessments and Screenings

Access to preventive health assessments and screenings is provided to diverse population of low-income children through the CHDP program. In 1997-98, over forty percent of all children from families with incomes up to 200 percent of FPL received at least one preventive medical exam through CHDP (SPM 1). The majority of the CHDP population is made up of young children, with 71 percent aged 0 through 5 years, 20 percent aged 6 through 12 years, and 9 percent aged 13 through 20 years. Of the children receiving services, approximately 63 percent are Hispanic, 11 percent White, 7 percent Black, 5 percent Asian, and the remainder are other or unknown ethnic groups. (Additional information on ethnicity of CHDP children is provided in Section 4.1.) In 1997-98, 2,285,697 children received CHDP services: 794,476 (34.8 percent) were in Fee-for-Service Medi-Cal; 442,525 (19.4 percent) were enrolled in Medi-Cal managed care plans; and 1,048,696 (45.9 percent) were covered by State funding. The number of children in the State-funded component of CHDP increased by 15.8 percent from 1996-97 to 1997-98.

Child Health Insurance

Assuring health care coverage for all children is a priority in California. An uninsured child is less likely to have a regular source of health care. The absence of a medical home is associated with less adequate preventive care and delayed and irregular treatment for acute and chronic health problems. In 1998, approximately 2 million children 0-18 years of age (21 percent) were uninsured (FPM 12) in California. Nationally, 15 percent of children were uninsured. The percent of children under 18 years of age without health insurance coverage in California increased from 16 percent in 1992 to 21 percent in 1998[18]. Part of this trend may be attributed to the delinkage of Medi-Cal and Temporary Assistance to Needy Families (TANF) benefits; some families that lost TANF benefits did not reapply for Medi-Cal despite their continuing eligibility. Transitional Medi-Cal coverage has been strengthened to address this problem. The percent of children with employment-based coverage did not change significantly from 1995-98 to offset the declining Medi-Cal enrollment. Another factor that may have played a role in the increase in uninsured children was the fact that many immigrant parents feared the consequences of applying for government programs, even for their citizen children. Clarification of the "public charge" concern was intended to reduce this fear.

A number of state-level approaches have been implemented to improve access to health services among children. Subsequent to the passage of the 1996 Federal Personal Responsibility and Work Opportunities Reconciliation Act welfare reform legislation, California enacted legislation to extend Medi-Cal eligibility to legal immigrants who arrived after August 1996, the cut-off for eligibility for federally-financed programs.

Following the passage of Title XXI, the State Children's Health Insurance Program, California created the Healthy Families Program (HFP) and expanded Medi-Cal eligibility. HFP was created on an insurance model to extend coverage to children in low-income working families. While originally providing coverage to children in families with incomes up to 200 percent FPL, HFP eligibility was extended to 250 percent FPL as of November 1999. To further increase enrollment, the State reduced the Healthy Families application from 26 to four pages, permitted a mail-in application, and allowed for 12-month continuous eligibility. Medi-Cal now accepts mail-in applications for children as well. Community outreach activities for public education and enrollment in Healthy Families and Medi-Cal were expanded. The Title V agency has collaborated with the Medi-Cal and Healthy Families programs to help insure access to care. Collaboration efforts have existed both at the Branch level and through the activities of the local MCH, CHDP, and CCS staff at county and local health departments.

Dental Health Services

Dental health services are a basic component of comprehensive primary care services. Nearly half of all preschool children and twelve percent of high school students in California had never visited a dentist. These figures are expected to improve with the introduction of the Healthy Families Program and Medi-Cal expansion, since both programs provide insurance coverage for dental services. The underlying barriers to dental care are lack of dental insurance and a limited number of providers serving low-income clients. In 1995, 28 percent of California children had no dental insurance. According to a recent study by the Center for California Workforce Studies, 97 of 487 (20 percent) Medical Service Study Areas--geographic regions defined by State agencies for the administration of various programs--are currently at or below the federal standard of one primary care dentist for every 5,000 people. Thirty-two Medical Service Study Areas, most of which are rural, do not have any dentists. Regions that have a shortage of dentists tend to have a higher percentage of minorities, lower median incomes and a higher percentage of children[31].

Current estimates suggest that less than 40 percent of dentists in California treat Medi-Cal patients; this figure is below the national standard of 50 percent. In addition, many dentists who do enroll in Denti-Cal (Medi-Cal) limit the number of Denti-Cal patients they will see. According to the study by the Center for California Workforce Studies, existing programs to address the shortage have not been successful in attracting dentists to underserved areas[31].

Ambulatory Care Sensitive Conditions: Asthma

The hospitalization rate for ambulatory care sensitive conditions is one measure of access to health services. Asthma is a medical condition that is commonly used to assess the extent to which children are receiving quality preventive care (HSI 1). Inadequate outpatient management of the condition or limited access to a medical home can result in increased asthma hospitalization rates. Among California's children, asthma is known to be a leading cause of hospital admissions and school absences[32]. State hospital discharge data indicate that asthma was the most common diagnosis for hospitalizations of 1-5 year olds, and the third most common diagnosis among 6-12 year olds in 1992[33]. In 1998, the rate of hospitalizations per 10,000 children less than five years old was 23.9 (HSI 1).
CMS, in collaboration with the Chronic Disease Prevention Division in the DHS, is developing a new multicomponent asthma program that is designed to increase awareness about asthma in young children age 0-5 years and result in more appropriate and timely interventions. The program includes community participation and training, "safety net" drug subsidies, and education of CHDP and CCS providers, to achieve early recognition, monitoring and treatment of asthma.

Health Services for Adolescents

Health care providers can play a role in the early detection of significant health problems and the modification of risky behaviors that contribute to adolescent morbidity and mortality. Despite the need, adolescents visit office-based physicians less often than any other age group. They are also more likely to be uninsured or under-insured than any other age group[7]. All of the Primary Care and Family Health programs are now working to incorporate a youth development approach and achieve better coordination. Opportunities for health examinations and preventive counseling are provided by CHDP and increasing the number of these assessments to provide annual visits for adolescents might be able to increase their impact on health risks and behaviors.

Health Services for Children in Foster Care

Children in foster care have higher rates of medical and developmental problems and have more limited access to health care. An estimated 112,528 children are in foster care in California and under county supervision. To address the problem of health care access, a new State program is being implemented which will use public health nurses in county and local health jurisdictions to ensure that children in foster care receive appropriate health services. This program is being carried out by CHDP conjunction with the California Department of Social Services.

- Access and enabling services for children with special health care needs

Outreach for CSHCN Services

Referral to the CCS program and outreach for CSHCN occurs through medical providers and many other health programs, such as CHDP, Medi-Cal, Healthy Families, WIC, the HIV Children's program, and the High Risk Infant Program. Referral and outreach through the new MVIP is anticipated. These services have population based, as well as

enabling components. Appropriate identification of the CSHCN population and referral is key in getting needed services to these children.

Access to Specialty Services

CCS case manages aspects of the medical care of CSHCN that are related to their CCS eligible condition and authorizes needed medical services, which are paid on a fee-for-service basis. These CCS authorized services are specifically "carved out" from the Medi-Cal and Healthy Families programs. In FY1998-99, 74 percent of children in CCS were enrolled in Medi-Cal and 3 percent were estimated to be enrolled in Healthy Families.

With the rapid changes in health care delivery systems, concerns about perceived decreasing access to quality medical care for CSHCN were raised by many individuals and groups contributing to the needs assessment. CCS staff, staff from local county health programs, medical providers, parent representatives, individuals representing managed care plans and children's hospitals, and the Senate Office of Research all indicated that the current key issue for CSHCN was maintenance of access to a network of specialty and subspecialty providers.

One issue impacting on medical provider availability is the low rate of reimbursement for pediatric medical specialty services. However, for most CCS medical providers there will now be more than a 50 percent increase in reimbursement over a two year period, due to a rate increase last year and increases included in the FY 2001 budget signed by Governor Davis. This should help sustain physician participation in CCS. Increases in reimbursement are also budgeted for other health care professionals who serve CCS children. A 30 percent increase is being provided to therapists and a 20 percent increase is being given to Special Care Centers.

Case Management

Through case management of the CCS eligible condition, the CCS program sees that CSHCN are referred to qualified specialty and subspecialty providers. However, the case managers in the county and State CCS program currently carry large caseloads that can exceed 500-1000 cases. The need for additional personnel, to facilitate case management, was also raised as a health care access issue.

The extent to which specialty medical care services are available and provided to CSHCN are evaluated in several of the Federal and State Performance Measures. CCS assures all of the categories of specialty and subspecialty services comprising FPM 2. Though California achieved a full score of 9, out of a maximum of 9 for the types of services offered CSHCN, it is the goal of CCS to continue to improve the individual accessibility and quality of those services.

Insurance Coverage

Potential access to health care is also evaluated by the percent of CSHCN who have a source of insurance for primary and specialty care (FPM 11). In 1999, 96 percent of CCS children had insurance; coverage included private sources as well as Medi-Cal. The CCS program assures payment for medical services related to the CCS eligible condition for eligible children without another source of coverage. The percent of CCS children who were insured met the 1999 State goal and efforts will continue to extend insurance coverage to all CSHCN.

Financial Eligibility

Last year when the income level for eligibility in the Healthy Families program was raised to 250 percent of the FPL, CCS income eligibility was extended for Healthy Families beneficiaries. This change allows all CSHCN enrolled in Healthy Families, who have a CCS eligible condition, to receive CCS services. However, the overall CCS financial eligibility level, of $40,000 annual family income or medical expenses equal to 20 percent of annual income, is viewed by some as too low. The possibility of extending the family income limits has been raised.

Provision of Services

The percent of California Supplemental Security Income (SSI) beneficiaries under 16 years of age who receive services from CCS (FPM 1) has steadily risen over the past four years. In 1999, 28.5 percent of SSI children received CCS services, exceeding the annual objective.

The percent of CSHCN with three sentinel conditions (spina bifida, cleft palate and ALL) who were referred for specialty medical care by CCS (SPM 2) was 79.2 percent in 1998, the last year for which information is currently available. However, as noted previously, the percent of CSHCN with these conditions is decreasing and this combined measure will not continue to be a useful indicator for access to care for California CSHCN.

Medical Home

The percent of CSHCN who have a medical/health home (FPM 3), can be viewed as an indicator of both health access and also of potential coordination of care. However, the optimum method for assessing this measure is unclear and identification of the medical provider who best serves as a medical home for specific categories of CSHCN is complex. The percent of CSHCN who had a medical home rose from 19.3 percent in 1997 to 32.2 percent in 1999, when medical home was defined as the listing of a primary care provider in CMS Net. CCS is actively collaborating in programs, with organizations such as the American Academy of Pediatrics and with a Title V grantee at Children's Hospital in Los Angeles, to define "medical home" for CSHCN. CCS is also working to increase the number of CSHCN with a medical home and is exploring possible incentives that will encourage medical providers to assume this challenging, time consuming role.

Referral for Neonatal Services

To assure that ill newborns receive treatment in hospitals with appropriate facilities and expertise, CCS approves Neonatal Intensive Care Units (NICUs) around the state for different levels of intervention and care (NICUs are designated as Intermediate, Community and Regional Level). CCS will only authorize services at NICUs appropriate for the infant's acuity. CCS requires NICUs below the Regional level to maintain relationships with higher level NICUs, for consultation and transport out of sick infants. These relationships also facilitate back transport of infants, to NICUs closer to home, as their medical condition improves.

Partnership with Families

Family participation in the CSHCN program (FPM 14) plays a major role in reducing institutional and cultural barriers to both health care access and coordination of services. The family is an essential partner in the CCS program. While California scored 14 out of a possible 18 on this FPM and met the annual objective for 1999, efforts are continuing to further improve family participation. Examples of these efforts are the statewide trainings that CCS has been sponsoring on family centered care.

The new Medically Vulnerable Infant Program will also provide in home evaluations and family support services. The program will encourage parental care giving and facilitate parent-health care provider interactions.

Population-Based Services

- Population based services for Pregnant Women, Mothers, and Infants

Expanded Alpha-fetoprotein Screening of Pregnant Women

Through the Genetic Disease Branch, prenatal testing is carried out to detect neural tube defects, other anomalies and genetic abnormalities that present with abnormal levels of alpha-fetoprotein. In 1998, 356,742 pregnant women received this testing and 840 were found to have confirmed fetal abnormalities

Genetic Screening of Newborns

Prevention, screening and early intervention for children who are born with genetic defects can prevent premature death and disability. As noted earlier, the Genetic Disease Branch of the Department of Health Services provides statewide prenatal and neonatal screening for the prevention of genetic or congenital disorders or the amelioration of their impact on individuals and families. A screening rate of approximately 99 percent of California newborns for metabolic and hematologic disorders has been consistently achieved from 1995-98 (FPM 4).

Newborn Hearing Screening

In 1999, 9.4 percent of newborns in California were screened for hearing impairment before hospital discharge (FPM10). It is anticipated that newborn hearing screening in California will increase dramatically over the next few years. The largest newborn hearing screening program in the U.S. will be fully implemented here by the end of 2002. The program is currently designed to screen infants born in CCS-approved hospitals, who comprise approximately 70 percent of births in California. If abnormalities are detected, CCS will assure the availability of further audiologic diagnostic evaluation.

SIDS

The SIDS Program has facilitated the SIDS Risk Reduction campaign, also known as Back to Sleep in California. The program has helped reduce the incidence of SIDS by nearly 50 percent. Since its inception in 1994, the SIDS rate has declined from 93.2 to 49.7 per 100,000 live births. The California SIDS Program worked in collaboration with the California Black Infant Health (BIH) Program to develop a SIDS Risk Reduction campaign for the African-American community. In addition, the SIDS Program has continued to work closely with the FIMR Program to understand the causes of SIDS deaths, as well as to identify areas of the community in need of additional outreach with the SIDS Risk Reduction message.

Child Care

As the numbers of working mothers entering the work force has increased, there is a growing awareness of the potential of child care centers as sites for health promotion activities. Local activities under development under the California Children and Families Initiative include training of child care providers in such areas as early childhood development, injury prevention, and the importance of preventive health services. Linkages with Title V supported enabling services for mothers and pregnant women can be developed with such programs as AFLP and BIH.

- **Population-based Services for Children**

Immunizations

Although immunization rates in California have increased significantly, vaccine-preventable illnesses remain a cause of morbidity and mortality among infants and children. By 1998, 75.9 percent of children 19-35 months of age were up-to-date on their vaccinations (FPM 5). California had achieved the national objective for three of the vaccines: measles-mumps-rubella combination, polio, and Haemophilus influenza type b (Hib). Coverage for the diphtheria, tetanus and pertussis vaccine reached 79 percent. Improved immunization coverage is a goal that CMS and MCH actively pursue through CHDP and local health departments. California is a pilot state for a Government Performance and Results Act (GPRA) immunization improvement project with CHDP measuring Fee-for-Service Medi-Cal immunization rates. County MCH staff often coordinate local interventions to improve vaccine coverage.

Lead Screening

The Federal General Accounting Office (GAO) released a report in January 1999, pointing out that children served by Federal health programs remain at significant risk for elevated blood lead levels. Seventy-seven percent of 1- 5 year olds with blood lead levels greater than 10 ug/dl were from low-income families served by programs such as Medicaid and WIC. In April 1999, the California State Auditor released a report which concluded that less than 10 percent of California children needing medical care and case management related to lead poisoning were being identified. Less than 25 percent of low-income children receiving health services through CHDP and Medi-Cal were having their blood lead levels tested. To address this issue, a targeted screening policy that requires blood lead screening in all low income children has been adopted and widely promulgated by the California Childhood Lead Poisoning Prevention program and CHDP and is being implemented in the CHDP population.

- Population based services for children with special health care needs

HIV Screening

The CCS HIV Children's program provides funding for screening, diagnostic evaluation, medical monitoring and follow-up for children and adolescents at-risk for or suspected of having HIV infection. Over 10,000 children have received services through this program. Children and adolescents identified as having an immunodeficiency problem are eligible for medical services authorized through CCS.

Hearing Screening in Neonatal Intensive Care Nurseries

Infants who receive treatment in a CCS approved intensive care nursery are required to receive hearing screening prior to discharge. Infants found to have abnormal screenings are referred for further audiologic evaluation. If a hearing deficit is diagnosed, it is a CCS eligible condition.

Infrastructure Building Services

- Infrastructure-building services for pregnant women, mothers, and infants

Local Infrastructure

Local health departments carry out, in collaboration with the State Department of Health Services**,** the core public health functions of assessment, policy development, and assurance to improve the health of their MCH populations in accordance. There are 58 counties and three cities, which have their own local health departments. The local MCH staff are central to assuring the populations' access to quality health care services for pregnant women and children, preventive and primary care services for children and

adolescents, and family-centered, community-based comprehensive health care services to children with special health care needs.

Perinatal Care

Care of high risk mothers at facilities providing complex perinatal care can reduce maternal morbidity and mortality (SOM 1). Very low birthweight infants are more likely to survive and thrive if their care is provided in a facility that is appropriately staffed and equipped, and serves a high volume of high risk deliveries and newborns. Since 1995, California has experienced a modest, but not statistically significant increase in the percent of VLBW infants delivered at facilities for high-risk deliveries and neonates (FPM 17). This percent increased from 60 percent in 1995 to 64.6 percent in 1998. The Regional Perinatal Programs and other prenatal outreach and education initiatives will continue to work to improve access to the appropriate level of facilities.

Training

Support is provided to seven schools of nursing to prepare graduate nurses for advanced practice in fields that facilitate access to cost effective primary care for women in the reproductive years, infants, children and adolescents. This support has enabled these programs to add faculty, expand sites for clinical practice, develop distance learning opportunities, develop new recruitment materials, and expand internet access to the programs. Training is provided to prepare certified nurse midwives, pediatric nurse practitioners and women's health care nurse practitioners. All of the programs have national and state accreditation for their courses of study in midwifery, women's health, pediatrics and school health. All schools have been able to increase the number of students enrolled with the support of the Maternal and Child Health Branch.

Monitoring and Assessment

The MCH Branch has implemented small area analysis through geographic information systems (GIS), as a tool in the effective targeting of limited public health resources. The first mapping projects have focused on teen births, the adequacy of prenatal care utilization, and most recently, the distribution of low birthweight births. By providing powerful but simple evidence of the location of the particular problem, the maps assist local agencies in planning resource allocation and program design and provide key documentation to agencies seeking funds for preventive interventions. These maps will facilitate the planning of outreach activities to target high-risk groups. The MCH Branch will work to integrate the GIS maps into the county planning process by assisting in the identification of local hot spots in which to focus interventions

Quality Assurance

The California Fetal and Infant Mortality Review (see Section 4.1) has been used as a local level tool to improve local health care systems and community infrastructure. Standardized infant death review systems are used to identify, evaluate, and determine

potential factors that contribute to a preventable infant death. Collected data are analyzed at both the local and state levels to define gaps in services or knowledge, to identify systems issues, to support system change, and to evaluate program effectiveness.

The California Perinatal Quality Care Collaborative (CPQCC) was developed in collaboration with the California Association of Neonatologists and the University of California at Berkeley School of Public Health. Its goal is to improve the quality and outcomes of perinatal health care in California. The Collaborative consists of participants from the public and private obstetric and neonatal provider community, health care purchasers, public health professionals, and business groups. The CPQQC objectives are to: (1) allow for the timely analysis of perinatal care, outcomes, and resource utilization based upon a uniform statewide process; (2) provide mechanisms for bench-marking and continuous quality improvement activities; and (3) serve as a model for other states. CPQCC will foster the development of an effective quality improvement infrastructure at state, regional, and hospital levels. Data is being reviewed to recommend quality improvement objectives, provide models for performance improvement, and assist providers in transforming data into information to improve care.

Perinatal Profiles is a project to improve services and outcomes for maternal and child health clients by providing up-to-date data on perinatal services, levels of risk, and perinatal outcomes for each of the State's perinatal regions, maternity hospitals, and birthing facilities. Perinatal Profiles are intended to promote quality improvement initiatives by supplementing a facility's internal quality assurance data. The data include level of care and risk-adjusted analysis for fetal, neonatal, and post neonatal mortality. MCH staff work with contract staff at the UC Berkeley School of Public Health and Regional Perinatal Program representatives to enhance the effectiveness of these reports.

- Infrastructure Building Services for Children

The local health departments provide the infrastructure to meet the needs of all segments of the MCH population.

CHDP Infrastructure Activities

The local CHDP programs screen and set standards for participating providers, perform quality assurance, and participate in CHDP planning and policy development with the CMS Branch. CMS provides guidance and carries out site visits and reviews of the county and local CHDP programs.

Data Systems Capacity Building

The types of services being provided to infants and children through the CHDP program are monitored through the CMS data analysis unit and the local CHDP programs. Aggregate information at a statewide level, and also county level data, are tracked in Sacramento, shared with the local programs and issued as an annual CHDP report. CHDP information used throughout this report comes from that data management effort.

Because of the many assessments, screenings, immunizations, care referrals, etc. contained in CHDP data, it is an important source of information for planning and policy development, as well as quality assurance monitoring. The CHDP program supplies 26 percent of the information used in national nutritional assessment and growth databases. As part of ongoing improvement within CMS, CHDP data is being continuously evaluated with respect to completeness and accuracy. CMS is also working with the Medi-Cal Managed Care Division, to improve data reporting on EPSDT services given through Medi-Cal managed care plans.

The GPRA immunization survey that is just being completed by CHDP in conjunction with Medi-Cal, is serving as a pilot program for future quality assurance and assessment analyses. The survey is utilizing both State administrative data and medical record based information to document immunization levels in young children. The process is increasing understanding of the capabilities and limitations of current State data bases. The information gathered, while necessary for Federal HCFA reporting, is also helpful for policy planning and as a reference against CHDP immunization data.

- Infrastructure Building for CSHCN

Coordination of Services Between CCS and Other Programs and Agencies

Assuring enrollment in CCS for eligible children in other health care programs and coordination of services were additional concerns of many participants in the needs assessment. Coordination issues included those between CCS and other programs, such as Healthy Families and Medi-Cal, and within CCS at the State and county level.

Staff liaisons in CCS are working with other programs to address between program issues. Specific CCS staff are designated to work with Medi-Cal, Medi-Cal Managed Care Plans and Healthy Families. CCS is represented on the Interagency Coordinating Council (ICC) for Early Start and is an active participant in the ICC Health Services Committee. Through ICC efforts and other CCS activities, such as the MTP, CCS is working to coordinate services for CSHCN with the Departments of Education, Developmental Services and other agencies. Coordination with the Department of Social Services is integral for services to children in foster care and SSI. CCS works with the Childhood Lead Poisoning Prevention Program to coordinate services for children found to have elevated blood lead levels.

Coordination of Services Within CCS State and County Programs

The statewide, CMS Net automated case management system is facilitating coordination within CCS, including CMS branch and individual county programs. CMS Net is also increasing data processing and assessment for the overall CCS population. The percent of CCS enrolled children registered in CMS Net (SPM 7) has been increasing and in FY 1998-99 rose to 18.5 percent. This progress has been slower than initially anticipated but,

with 45 counties entering data into the system now, it is anticipated that over 53 percent of current CCS children will be on CMS Net by the end of calendar year 2000.

Coordination with and support of county CCS programs is carried out on other levels. CMS Branch offices serve as consultation centers for CCS programs in independent counties and provide direct case management for the dependent counties. CMS Statewide conferences and conference calls address county questions and provide dialogue on program issues, as do CMS Branch site visits and county reviews. CMS also provides trainings in locations in the northern and southern parts of the state, on CCS related issues.

Coordination of CCS activities with programs at the community level is carried out through the county programs and community based MTUs. CMS branch site visits to community facilities, seeking and wishing to maintain CCS approval, assures that they meet CCS standards.

CCS Standards

Maintenance of standards for health care services and quality assurance activities were identified as concerns of some of the needs assessment participants, particularly with respect to CSHCN. CCS develops standards for hospitals, intensive care units, special care centers, and paneling of health care providers, who wish to participate in CCS programs. New standards for CCS approval of NICUs were issued in 1999 and CCS has participated in outreach sessions, to clarify any questions about the standards. Reviews of NICUs for CCS reapproval, based on the new standards, will begin this year. New CCS standards for Neonatal Surgery Centers and Special Care Centers are being developed.

Collaborative Relationships With Other Organizations

CMS has numerous collaborative relationships with organizations concerned with health care for children. Examples include: work with the American Academy of Pediatrics, California District on the medical home issue; the California Association of Neonatologists and University of California at Berkeley, School of Public Health on the California Perinatal Quality Improvement Program and maintenance of the provider network; and the California Children's Hospital Association on issues relating to access to care. (Please see further discussion in Section 4.2., Other Program Activities.)

Health Status Indicators

California data for the Core Health Status Indicators (HSI). Data for all Core HSI are included. Retrospective figures from 1994-1998 are included for measures 1, 3, 4A, 4B, 5A, and 5B.
Data for calendar year 1998 are presented for HSI 2A, 6 and 7.

/2002/ Data for 1999 are presented for HSI 1,2A,3,4A,4B,5A,5B,6A-D, 7A-C and 8.

/2003/ Data for 2000 are presented for HSI 1,2A,3,4A,4B,5A,5B,6A-D, 7A-C and 8.

/2004/ Data for 2001-2002 are presented in Forms 2-21 and discussed in the Health Systems Capacity Indicators section of the narrative.

Priority Needs

The five year needs assessment has led to the identification of the following priorities for the population of pregnant women, mothers, infants, children, and CSHCN for the period of FFY 2001-2005. The priority needs encompass all levels of the health services pyramid and in some cases span pyramid levels.

The main priority need identified that relates to direct health care services is the need to maintain and improve the State health care programs for children and particularly CSHCN. These programs, CHDP and CCS, are the core "safety net" for children's health care in the state.

A number of priority needs were identified that relate to enabling services. The major needs in this area concern: racial and ethnic disparities in infant health and mortality; existing disparities in the proportion of low birthweight; issues of access to maternal health care; issues of access to health care for children and CSHCN; and the presence of community, family and domestic violence.

Priority needs relating to population based services are: the large number of adolescents giving birth; low breast-feeding rates; and high intentional and non-intentional injury rates. Other population-based concerns are: the need for promotion of healthy lifestyle practices for children and adolescents; and the need for outreach through health programs to aid catchment of CSHCN.

An identified priority need for infrastructure building relates to the quality of maternal health care. Many of the ethnic disparities in infant health care and proportion of low birthweight infants also relate to infrastructure issues. Infrastructure building is pertinent to State priority needs for children with respect to: the quality of primary and specialty care providers for children and CSHCN; better coordination of services for CSHCN; and the need to expand the capabilities of the statewide case management and data collection system for CSHCN (CMS Net).

The following California priorities, for Title V activities over the next five years, were developed based on the priority needs in the state:

California Title V Priorities

- Eliminate racial and ethnic disparities in infant health, including gaps in the infant mortality rate and the proportion of low and very low birthweight live-born infants.
- Promote safe motherhood by improving early access to and the quality of maternal health care for all women.
- Improve access to quality primary and specialty care providers, including dental, for all children, particularly Children with Special Health Care Needs.
- Reduce the adolescent birth rate.
- Increase breastfeeding rates among newborns.
- Promote healthy lifestyle practices among children and adolescents with emphasis on smoking prevention, adequate nutrition, regular physical activity, and oral health.
- Decrease intentional and unintentional injury death rates among children and adolescents.
- Reduce the prevalence of community, family, and domestic violence.
- Improve coordination and outreach with other health programs to facilitate delivery of health care services to Children with Special Health Care Needs.
- Continue to expand the CCS statewide automated case management and data collection system, CMS Net, to improve tracking and monitoring services and outcomes for CSHCN.

Annual Budget and Budget Justification

Completion of Budget Forms

See detailed information in Forms 2,3,4, and 5.

Other Requirements

Since the enactment of OBRA 89, California has maintained the availability of funds under both the maintenance of effort and the match requirements. The California Title V agency will continue to do so in the coming year.

The proposed allocation of Title V funds for California for FFY2001 is $43,010,496. The proposed activities are based on this figure. Preventive and primary services for pregnant women, mothers, and infants are designated to receive $13,619,786 (31.67 percent of the total), preventive and primary services for children to receive $14,122,761 (32.83

percent), and CSHCN to receive $13,054,925 (30.35 percent). Administrative costs are proposed at $2,213,024 (5.15 percent).

/2002/ The proposed allocation of Title V funds for California for FY2002 is $42,994,205. Preventive and primary services for pregnant women, mothers, and infants are designated to receive $13,279,689 (30.89 percent of the total), preventive and primary services for children to receive $14,284,664 (33.22 percent), and CSHCN to receive $13,216,828 (30.74 percent).

/2003/ The proposed allocation of Title V funds for California for FY2003 is $44,289,287. Preventive and primary services for pregnant women, mothers, and infants are designated to receive $13,920,846 (31.43 percent of the total), preventive and primary services for children to receive $14,525,388(32.80 percent), and CSHCN to receive $13,420,028 (30.30 percent).

/2004/ Please refer to the Budget section of the new narrative.

State Match/Overmatch

California will receive $43,010,496 in Federal Title V Block Grant funds for FFY 2001. The required match is $32,257,872. California's FFY 2001 expenditure plan for MCH programs includes $664,726,146 in State funds. Consequently, the state-funded expenditures for preventive and primary health care services for the Title V populations exceeds the required 4:3 matching ratio.

/2002/ California will receive $42,994,205 in Federal Title V Block Grant funds for FFY 2002. The required match is $32,245,654. California's FFY 2002 expenditure plan for MCH programs includes $772,185,068 in State funds. Consequently, the state-funded expenditures for preventive and primary health care services for the Title V populations exceeds the required 4:3 matching ratio.

/2003/ California will receive $44,289,287 in Federal Title V Block Grant funds for FFY 2003. The required match is $33,216,965. California's FFY 2003 expenditure plan for MCH programs includes $777,395,553 in State funds. Consequently, the state-funded expenditures for preventive and primary health care services for the Title V populations exceed the required 4:3 matching ratio.

/2004/ Please refer to the Budget section of the new narrative.

Documentation of Fiscal Restrictions

Administrative Costs Limits

In FFY 2001, no more than 10 percent of the Federal Title V MCH Block Grant funds will be used for administrative costs related to each program component. During FFY 2001, California will expend only 5.15 percent of Title V funds on administrative costs.

/2002/ In FFY 2002, no more than 10 percent of the Federal Title V MCH Block Grant funds will be used for administrative costs related to each program component. During FFY 2002, California will expend only 5.15 percent of Title V funds on administrative costs.

/2003/ In FFY 2003, no more than 10 percent of the Federal Title V MCH Block Grant funds will be used for administrative costs related to each program component. During FFY 2003, California will expend only 5.47 percent of Title V funds on administrative costs.

/2004/ Please refer to the Budget section of the new narrative.

Definition of Administrative Costs

In this Application, administrative costs are defined as the portion of the Title V dollars used to support staff in the MCH and CMS Branch Operations Sections. Funds supporting State program and data staff (but not administrative staff) in the MCH and CMS Branches are considered to be program rather than administrative costs.

Administrative costs include staff and operating costs associated with the administrative support of specific MCH Branch and CMS Branch programs. These support functions include, but are not limited to, contract management, accounting, budgeting, personnel, audits and appeals, maintenance of central contract files, and clerical support for these functions.

"30-30" Minimum Funding Requirement

At least 30 percent of the MCH Title V Block Grant funds will be used for children's preventive and primary care services delivered within a system which promotes family-centered, community-based, coordinated care. At least 30 percent of the Title V Block Grant funds will be used to provide services to CSHCN delivered in a manner which promotes family-centered, community-based, coordinated care.

/2003/ In some cases, the DHS uses estimates to assess expenditures for both individuals served and the types of services provided. These estimates are based on the target population and program activities authorized in statute, excluding the State budget, and specified in the scope of work for each contractor. Requiring contractors to bill according to actual amounts spent on each type of individual served and by service

provided is not possible within current administrative and fiscal policies. Changing State contractual policies would result in undue financial and administrative hardship to local governments and non-profit community-based organizations. This added burden without increased funding would result in many of them not being able to continue to provide needed services to women and children in the state.

Maintenance of State Effort

The State Department of Health Services has an ongoing commitment to provide maternal and child health services to women and children within the State of California. This commitment includes continued support to local health jurisdictions, local programs, clinics and Medi-Cal providers for maternal and child health services.

It is the State's intent to ensure that State General Fund contributions to these local programs, which are also funded in part by the Federal Title V Block Grant, be administered by the MCH and CMS Branches. The State's General Fund contribution for FFY 2001 is $664,726,146, which is $557,567,396 greater than the State's General Fund contribution of $87,158,750 in base year FFY 1989.

/2002/ The State's General Fund contribution for FFY 2002 is $772,185,068, which is $685,026,318 greater than the State's General Fund contribution of $87,158,750 in base year FFY 1989.

/2003/ The State's General Fund contribution for FFY 2003 is $777,395,553 which is $690,236,803 greater than the State's General Fund contribution of $87,158,750 in base year FFY 1989.

/2004/ Please refer to the Budget section of the new narrative.

Additional Program Budget Information

Other Funds

The State Children's Health Insurance Program (Title XXI of the Social Security Act) makes available Federal funds for states to expand health insurance to uninsured children. California's response to this legislation is the Healthy Families Program. With this program, California has expanded access to health coverage for uninsured children through:

1) A health insurance program for infants and children whose family incomes are above those which provide eligibility for no-cost Medi-Cal but are at or below 250 percent of the FPL (this was increased from 200 percent of the FPL in November 1999).
2) Changes to the Medi-Cal system, which simplifies eligibility to increase enrollment of the eligible population.
3) Coverage through the Access for Infants and Mothers (AIM) program of infants up to 12 months whose family income is between 200 and 250 percent of the FPL.

Performance Measures

National "Core" Five Year Performance Measures

Figure 3
TITLE V BLOCK GRANT
PERFORMANCE MEASUREMENT SYSTEM

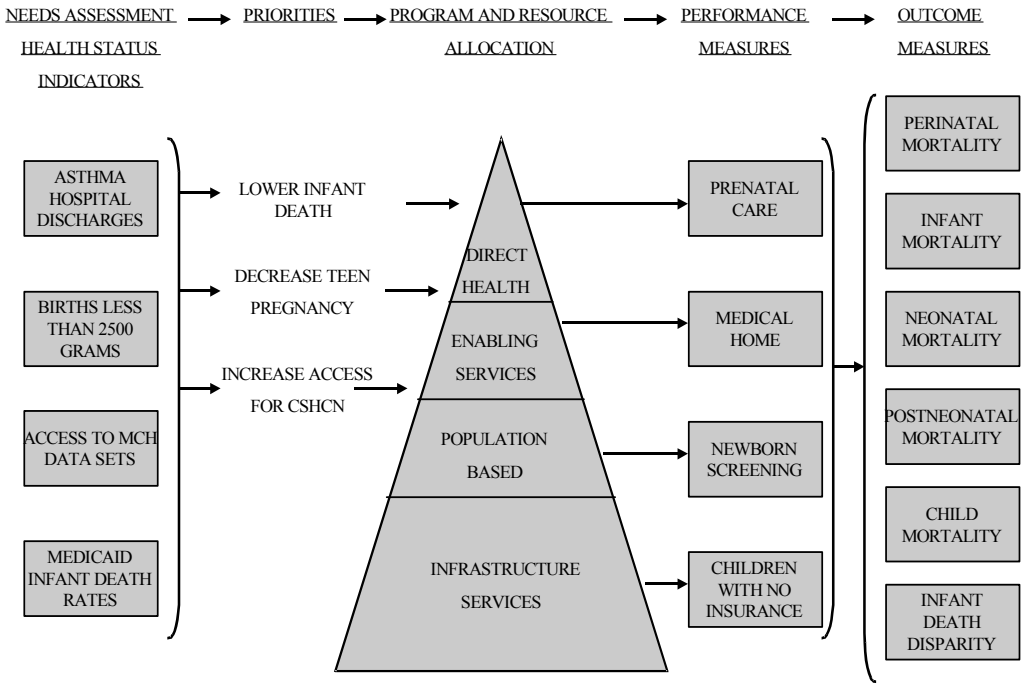

Figure 4
PERFORMANCE MEASURES SUMMARY SHEET

Performance Measure	Pyramid Level of Service				Type of Service		
	DHC	ES	PBS	IB	C	P	RF
1) The percent of State SSI beneficiaries less than 16 years old receiving rehabilitative services from the State Children with Special Health Care Needs (CSHCN) Program.	X				X		
2) The degree to which the State Children with Special Health Care Needs (CSHCN) Program provides or pays for specialty and subspecialty services, including care coordination, not otherwise accessible or affordable to its clients.	X				X		
3) The percent of Children with Special Health Care Needs (CSHCN) in the State who have a "medical/health home"		X			X		
4) Percent of newborns in the State with at least one screening for each of PKU, hypothyroidism, galactosemia, hemoglobinopathies (e.g. the sickcle cell diseases) (combined).			X				X
5) Percent of children through age 2 who have completed immunizations for Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, Hepatitis B.			X				X
6) The birth rate (per 1,000) for teenagers aged 15 through 17 years.			X				X
7) Percent of third grade children who have received protective sealants on at least one permanent molar tooth.			X				X
8) The rate of deaths to children aged 0-14 caused by motor vehicle crashes per 100,000 children.			X				X
9) Percentage of mothers who breastfeed their infants at hospital discharge.			X				X
10) Percentage of newborns who have been screened for hearing impairment before hospital discharge.			X				X
11) Percent of Children with Special Health Care Needs (CSHCN) in the State CSHCN program with a source of insurance for primary and specialty care.				X	X		
12) Percent of children without health insurance.				X	X		
13) Percent of potentially Medicaid eligible children who have received a service paid by the Medicaid				X		X	

Program							
14) The degree to which the State assures family participation in program and policy activities in the State CSHCN program				X		X	
15) Percent of very low birth weight live births				X			X
16) The rate (per 100,000) of suicide deaths among youths 15-19.				X			X
17) Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates				X			X
18) Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester				X			X

NOTE: DHC = Direct Health Care ES = Enabling Services PBS = Population Based Services IB = Infrastructure Building C = Capacity P = Process RF = Risk Factor

	Pyramid Level of Service				Type of Service		
	DHC	ES	PBS	IB	C	P	RF
1. The percent of children whose family income is less than 200 percent of the Federal Poverty Level who received at least one preventive medical exam during the fiscal year.	X						X
/2002/ 2. The percent of low-income children who are above the 95th percentile of weight-for-height, or overweight.			X				X
3. The rate of deaths caused by drowning in swimming pools per 100,000 children aged 1 through 4 years.			X				X
4. The rate of deaths caused by homicide per 100,000 adolescents aged 15-19 years.			X				X
5. The rate of deaths caused by motor vehicle injuries per 100,000 adolescents aged 15-19 years.			X				X
6. The incidence of neural tube defects (NTDs) per 10,000 live births and fetal deaths among counties participating in the California Birth Defects Monitoring System							
7. The percent of California Children's Services (CCS) enrolled children registered in CMS Net, the statewide automated case management and data collection system for CCS.							
8. The percent of youth aged 13-17 years who report having smoked a cigarette in the past 30 days.			X				X
9. The percent of women at least 18 years of age who report experiencing intimate partner physical abuse in the past 12 months.		X					X
10. The percent of low-income children enrolled in California's Child Health and Disability Prevention program who were above the 95th percentile of weight for height./2002/Changed to SPM 2.			X				X

NOTE: DHC = Direct Health Care ES = Enabling Services PBS = Population Based Services
IB = Infrastructure Building C = Capacity P = Process RF = Risk Factor

Five Year Performance Objectives

Please see Form 11 for specific annual objectives.

/2002/ Trend analysis was applied by the Title V agency to the development of the annual objectives for those Performance Measures for which a statistically significant trend was observed from 1996-1999 (or the period relevant to the specific measure). It should be noted that in these trend analyses, cause-specific mortality measures were not adjusted for the potential impact of the transition from the ICD9 to the ICD10 codes in 1999. The uncertainty regarding the precise influence of this change on the specific measures for the relevant age groups precludes the application of a precise adjustment factor at this time. Caution is advised in the examination of changes in these measures between 1999 and prior years. The MCH Branch will be assessing the impact of the change in diagnostic codes on each of the relevant measures and indicators over the coming year in order to address this methodological issue in next year's Title V application. For those measures where no statistically significant time trend was observed, data were available for too short a time period to allow for trend analysis, or the available data were not comparable over the time period because of changes in methodology, collective knowledge was the basis of the annual objectives.

/2003/ Several analytic strategies were applied in the development of the annual objectives for 2001 through 2007. Trend analyses were conducted using simple linear regression techniques based on both the last five years of data (1996-2000) and the last four years of available data (1997-2000). In those cases, where the change from 1996-1997 differed markedly from the annual change observed in the past four years, the four-year analysis was selected for the development of objectives. It should be noted that in these trend analyses, cause-specific mortality measures were not adjusted for the potential impact of the transition from the ICD9 to the ICD10 codes in 1999. The uncertainty regarding the precise influence of this change on the specific measures for the relevant age groups precludes the application of a precise adjustment factor at this time. Caution is advised in the examination of changes in these measures between 1999 and prior years.

Regression analyses were considered in setting annual objectives based on both p and R square values. In instances where the regression analysis yielded a p value <0.05 but the Title V data team considered it highly unlikely that the same rate of change could be maintained through 2007, the annual objectives were adjusted based on collective knowledge. Collective knowledge was also the basis of setting the annual objectives for those measures/outcomes where data were available for too short a time period to allow for trend analysis or the available data were not comparable over the time period because of changes in methodology. The proposed fiscal reductions for California in FY2002-03 and the likely impact it will have on the availability of services for women, infants, children and adolescents, as well as the economic hardships that may face more of California's most vulnerable families, were also considered in the development of the annual objectives.

/2004/ There were no changes in the methodology to develop the annual objectives; the same strategies were used for FY 2003-2004.

State "Negotiated" Five Year Performance Measures

Development of State Performance Measures

The selection of the State Performance Measures is based on a number of considerations. The major criteria include the following:

a) The needs assessment conducted in preparing the Title V application highlighted the importance of the problem either in terms of its being a major contributor to mortality and/or morbidity in a maternal, infant, child, or CSHCN population group, or the assessment indicated a deteriorating situation worthy of ongoing monitoring. Input from the local jurisdictions, the stakeholder community, and the statewide review was also used to determine importance and relevance of the problem for California.
b) The State of California has demonstrated a strong commitment to addressing a specific health problem such as reducing the teen birth rate, the prevalence of domestic violence, and tobacco use among California's youth.
c) Effective and affordable interventions can be identified to address the health problem.
d) Reliable and valid data to monitor the problem are available from existing data systems.
e) Existing programs merit continuing support to achieve further improvement in areas related to the State's Title V priorities.

Discussion of State Performance Measures

State Performance Measure 1 is the percent of children whose family income is less than 200 percent of FPL who received at least one preventive medical exam during the fiscal year.

Insuring appropriate health service utilization often depends on more than health insurance coverage. The availability of providers who are geographically and culturally accessible can also affect utilization. Preventive medical examinations are an ideal method for the identification and early intervention of medical conditions. While it would be desirable to measure whether all children have received the age-appropriate recommended preventive health services at appropriate intervals, California does not currently have this capability. Nevertheless, the CMS Branch is able to track whether low-income children have received at least one preventive medical examination per year, using the CHDP program data. This measure provides an indication of whether California's low-income children are accessing the services for which they are eligible for financial coverage through Medi-Cal or CHDP. However, the FY1997-98 data does not yet include Healthy Families, which began enrollment in July 1998. Over time, the measure will help assess whether expanding health care coverage is actually increasing access to and utilization of care. It should be noted that annual health examinations and screenings are not currently provided by CHDP, for children over age 3 years.

Assessments every 2-3 years are included. Therefore, a score approaching 100 percent on this measure is not currently achievable. In FY 1997-98, 4,832,348 children in California were from families with incomes up to 200 percent of FPL. 40.2 percent of these children received a health service through CHDP.

/2002/ In FY 1998- 1999, 41.5 percent of children from families with incomes up to 200 percent of FPL received preventive health examinations through CHDP[13]. However, the score on SPM 1 remains an underestimate of the health services provided to low-income children in California, since it does not include Health Families data, which is not yet available. There are also concerns that encounter data on children enrolled in Medi-Cal Managed Care is currently being underreported.

SPM 1 is directly related to the State Title V priority of improving children's access to primary and specialty care. It measures a direct health care service that relates to the risk factor of low-income. Timely diagnosis and treatment of medical problems can contribute to reducing infant and child mortality and mortality rates. Preventive exams and screenings provide critical opportunities for identification of problems that may interfere with normal development or school performance, as well as opportunities for health promotion counseling related to breastfeeding, diet, physical activity, and injury prevention.

State Performance Measure 2 is the percent of CCS children with Cleft Palate, Spina Bifida, and Acute Lymphoid Leukemia who were referred to Special Care Centers for multidisciplinary, coordinated evaluation and treatment plans.

This measure was initially chosen as a means of monitoring appropriate referral and access to care for CCS children. However, the number of children with these conditions is decreasing and the relevance of this subset of diagnoses to the overall CCS population is diminishing. This performance measure will be deleted in future application/ reports. As CMS Net expands (**State Performance Measure 7**) and CCS data capabilities increase, other, broader based assessments of care delivered by the CCS program will become available.

/2002/ The measure concerning CCS children with Cleft Palate, Spina Bifida, and Acute Lymphoid Leukemia has been dropped. **State Performance Measure 10** from last year's application is now **State Performance Measure 2**, the percent of low-income children who are above the 95th percentile of weight-for-height, or overweight. Please see discussion of this measure under **State Performance Measure 10.**

State Performance Measure 3 is the rate of deaths per 100,000 children aged 1 through 4 years caused by drowning in swimming pools.

Drowning has remained a leading cause of injury death to children ages 1 through 4 in California for the past decade. SPM 3 is directly related to the State's priority of childhood injury prevention. The intervention strategies are population-based and

address the risk factor of access to swimming pools among young children. Effective prevention efforts can contribute to continuing declines in the child mortality rate.

State Performance Measure 4 is the rate of homicide related deaths per 100,000 adolescents aged 15-19 years.

Homicide is the second leading cause of death among adolescents aged 15 through 19 years in California, following closely behind motor vehicle deaths. In 1998, there were 17.1 deaths per 100,000 adolescents aged 15 through 19 years. The corresponding figure for African American adolescents was 48.2 deaths, and for Latinos, 28.9 deaths per 100,000 15 through 19 year olds. SPM 4 relates to the priority need of injury prevention in childhood and adolescence. Interventions for homicide prevention are population-based and address the risk factors associated with homicide deaths such as access to firearms. The prevention of homicide deaths contributes to the reduction of the child mortality rate.

State Performance Measure 5 is the rate of deaths resulting from motor vehicle injuries per 100,000 adolescents 15-19 years of age.

In 1998, California's motor vehicle mortality rate was 17.2 per 100,000 adolescents aged 15 through 19 years. Although motor vehicle related deaths are decreasing, they remain the number one cause of death in this age group. SPM 5 is directly related to the priority need of childhood injury prevention. The interventions are population-based and address the risk factors associated with adolescent development such as alcohol and illicit drug use and limited driving experience. The reduction of motor-vehicle related injury deaths will contribute to the reduction of the overall child mortality rate.

State Performance Measure 6 is the incidence of neural tube defects (NTDs) per 10,000 live births plus fetal deaths among counties participating in the California Birth Defects Monitoring Program (CBDMP).

Focus on the problem of NTDs is based primarily on the preventable nature of this devastating condition more than the numbers of newborns and families affected. The Centers for Disease Control and Prevention estimate that 50 percent of neural tube defect births could be prevented. In 1997, there were 134 NTDs among 252,159 live births and fetal deaths registered in CBDMP, for a rate of 5.3 NTDs per 10,000 live births and fetal deaths. SPM 6 relates to the priority of reducing ethnic and racial disparities in infant health status. The programs are population-based and address the known risk factors associated with the occurrence of NTDs such as a prior infant born with NTDs. The State Performance Measure also addresses the health outcome measures of improvement of infant mortality as well as neonatal, post-neonatal, and child mortality rates.

State Performance Measure 7 is the percent of California Children's Services (CCS) enrolled children registered in CMS Net, the statewide automated case management and data collection system for CSHCN.

This performance measure addresses coordination of care of the CSHCN population. In the past, each individual county CCS program had its own case management and data tracking system, with different formats, that did not communicate with each other or with State systems. CMS Net was developed to create a common format for case management and data collection. The information stored on CMS Net, about CCS children and authorized health services, is accessible to each county. As counties come into the CMS Net system, coordination of services between counties is improving. Statewide information on the overall CCS program is also becoming available to monitor the health services provided, perform quality assurance, track health outcomes and formulate CCS policy.

/2002/ CMS Net allows determination of the actual number of active cases in the statewide CCS program at any given time. For counties not on CMS Net, beneficiary numbers are currently determined from individual data systems, county estimates and paid claims data. As more counties join CMS Net, the accuracy of program data will increase. As of May 8, 2001, 46 counties were on CMS Net and 42,383 active cases, or approximately 29 percent of all CCS cases, were entered in the system [37].

Proposed New State Performance Measures

/2002/ These measures have been adopted by the California Title V agency and are incorporated in this year's application.

State Performance Measure 8 is the percent of women at least 18 years of age who reported being the victims of intimate partner physical abuse during the past twelve months.

In California, 196,832 incidents of domestic violence were reported to law enforcement, and 56,892 domestic violence arrests were made in 1998. According to population-based data collected in the 1998 CWHS, 6.0 percent of women aged 18 years and older were victims of intimate partner physical abuse in the past twelve months. The violence impacts the family as well as the woman. The CWHS data indicate that about 71 percent of intimate partner physical domestic violence (IPP-DV) victims have children younger than 18 at home compared to 46 percent of the women who are not victims. IPP-DV victims also have a substantially higher proportion of children aged 1 to 5 in their households (42.9 percent) compared to women who are not victims of IPP-DV (23 percent).

The adoption of this performance measure is based on both the scale of the problem and the level of State commitment to prevention. Since 1994, a number of California laws have been passed to protect and assist women who are victims of intimate partner abuse. The Battered Women's Shelter Program was established in 1994 as a result of legislative action, and funds direct shelter services for abused women and their children and community prevention activities.

Proposed SPM 8 is directly related to the MCH priority of reducing domestic, family, and community violence. The services provided by the Domestic Violence Section of the MCH Branch are primarily enabling services. They address the risk factors that are associated with the incidence of domestic violence. Existing Federal Outcome Measures do not relate directly to the proposed State Performance Measure but can be indirectly related to infant and child death rates.

State Performance Measure 9 is the percent of 12-17 year olds who report smoking cigarettes in the past thirty days.

California has witnessed marked declines in the rate of smoking among the adult population. Similar gains have not been observed among youth. In 1998, 10.7 percent of youth 12-17 years old reported smoking cigarettes in the past thirty days. Based on data from the California Tobacco Control Section, this percent has shown no significant change over the past five years. Tobacco is the number one preventable cause of death. More than 80 percent of adult smokers had tried smoking by their 18th birthday and more than half had become regular smokers by that time. One of every three of the young people who become regular smokers each day nationally will have their lives shortened from tobacco-related diseases.

A portion of the funds becoming available to the State and counties from the cigarette surtax imposed following the passage of Proposition 10 will be allocated to youth smoking prevention. This State Performance Measure reflects California's commitment to the reduction of youth smoking. It relates directly to the priority need of improving the lifestyles of the state's children and adolescents. Services are population-based and designed to address specific risk factors. Federal Outcome Measures do not relate directly to the problem of youth tobacco.

State Performance Measure 10 is the percent of low-income children who are above the 95th percentile of weight for height, or overweight.

/2002/ As noted above, this measure now becomes State Performance Measure 2.

/2003/ See **State Performance 2** for this measure.

The prevalence of overweight among California's children is higher than the national average and is increasing annually according to data collected in the Pediatric Nutrition Surveillance System[34]. The California data for this system comes from CHDP. Sedentary lifestyle and dietary habits contribute to the problem. Among the over two million low-income children served in the CHDP program in 1998, 14.1 percent had weights for height above the 95th percentile. This figure has increased gradually from 12.3 percent in 1991. The State's concern with pediatric overweight relates to the association of childhood weight problems with adult overweight and obesity, and the increased risk of a number of chronic diseases, such as high blood pressure, Type II diabetes, stroke and heart disease. In addition, childhood overweight serves as a sentinel event for broader issues of unhealthy lifestyle practices. Population-based interventions to promote optimal child health through regular physical activity and a healthy diet are

necessary to prevent pediatric overweight and obesity. Without preventive interventions to address the problems of poor diet and lack of regular physical activity, the observed trend of increasing pediatric obesity and overweight is likely to continue.

State Performance Measure 10 relates directly to the priority need of improving the lifestyles of California's children and youth. Outcome measures do not relate directly to the problem of childhood overweight and obesity**.**

/2003/ No changes were made in the State Performance Measures in the FY2002-03 application/report.

/2004/ Starting with the year 2000, the CHDP data used for the Pediatric Nutrition Surveillance System has been updated to utilize the 2000 CDC growth chart percentiles. However, this new data system was not incorporated into the Title V report for FFY2000, as the information was not received in time. CDC also has unduplicated the data for FY200; improving accuracy and resulting in smaller numbers for both the numerator and the denominator.

For FFY2001, the number of children aged 0 to 12 years registered in the CHDP program with a weight for length measurement (for children under 2 years) or a BMI (for children aged 2 to 12 years) is 1,214,543 compared with 1,732,531 in FY2000. The number of children age 0 to 12 years served in the CHDP program who have weights for length or BMIs-for-age at or above the 95th percentile for FFY2001 is 208,376 compared with 258,147.1 for FY2000. The percentage of overweight children for FFY2001 is 17.2 percent compared with 14.9 percent for FFY2000. The latter was probably an underestimate, and the former is a more accurate estimate; the FFY2002 data will allow for a comparison. Nevertheless, 17.2 percent is 3.2 percent above the performance objective, and contributes to the impetus for CDHS to identify resources necessary to implement a long-term strategic plan to combat overweight and obesity.

Five Year Performance Objectives

Please see Form 11 for specific information on the Annual Objectives established for each State Performance Measure.

Review of State Performance Measures

The State Performance Measures will be reviewed by central and regional staff of the Maternal and Child Health Bureau. Discussions and negotiations will be carried out with State MCH and CMS Branch staff during the application and annual report review session.

Outcome Measures

Please see Form 12 for specific information on the Outcome Measures. Form 16 provides the detail sheet for the State Outcome Measure, maternal mortality.

Endnotes

1. City/County Population Estimates, State of California, Department of Finance, May/2000.

2. County Population Projections with Race/Ethnic Detail July 1, 1990-2040 in 10-Year Increments, State of California, Department of Finance, December 1998.

3. State of California, Department of Finance Press Release, 2/9/2000.

4. Actual and Projected Births by County, State of California, Department of Finance, 12/08/99.
5. Race/Ethnic Population with Age and Sex Detail, 1970-2040. Sacramento, CA, December 1998.

6. CCS Program data.
7. Clayton SL, Brindis, CD, Hamor JA, Raiden-Wright H, Fong, C. (2000). Investing in Adolescent Health: A Social Imperative for California's Future. San Francisco, CA: University of California, San Francisco. National Adolescent Health Information Center.

8. County Population Projections with Racial/Ethnic Detail, Estimated July 1, 1990-96, Projections for 997-2040. California Department of Finance, December 1998.

9. Profile of the Foreign-Born Population in the United States: 1997, Current Population Report Special Studies P23-195, US Census Bureau, Washington D.C.

10. Managed Care Annual Statistical Report, April 1999, Medical Care Statistics Section, California, Department of Health Services.

11. http://www.mrmib.ca.gov/MRMIB/HFP/HRPEptSum.html.
12. State of California, Department of Finance, City/County Population Estimates, with Annual Percent Change, January 1, 1999 and 2000. Sacramento, California, May 2000.

13. Current Population Survey, 1999.

14. National Survey of America's Families, Urban Institute Jan. 1999, Washington, DC.
15. Managed Care Annual Statistical Report, Medical Care Statistics Section, DHS, April 1999, Sacramento, California.

16. CHDP Program data.
17. Healthy Families Program Subscribers Enrolled by Age; By Gender June 5, 2000, http:/www.MRMIB/HFP/HFPRpt2.html.

18. HH Schauffler and ER Brown. *The State of Health Insurance in California, 1999.* Berkeley, CA: Regents of the University of California, January 2000.

19. California Birth Certificate Data, 1998; Vital Statistics Section, Center for Health Statistics.

20. AIMEnrollmentData2/92to11/98; http://www.mrmib.ca.gov/MRMIB/AIMFB99/AIM3.html.

21. Medical Care Statistics Section, 1998-99 Program Data.

22. Family P.A.C.T. Program Highlights; California Department of Health Services, Office of Family Planning, Nov. 1999; http://www.dhs.ca.gov/org/pcfh/ofp/FamPACT/proghi.htm.

23. SCHIP Annual Report Federal Fiscal Year 1998.

24. California's Medical Assistance Program Annual Statistical Report, Calendar Year 1998,
Medical Care Statistics Section, California Department of Health Services.

25. Office of AIDS, California Department of Health Services.

26. Shaw F., Velie E., Wasserman C. Risk for Neural Tube Defect-Affected Pregnancies among Women of Mexican Descent and White Women in California. American Journal of Public Health 1997;87:1467-71.

27. Rayburn, W.F., Stanley, J.R., and Garrett, M.E. Periconceptional folate intake and neural tube defects. Journal of the American College of Nutrition 1996;15(2):121-125.

28. Maternal Mortality in Los Angeles County 1994-96, County of Los Angeles – Department of Health Services Family Health Programs, Fetal-Infant Mortality Review Project, May 1998.

29. Skager R. and Austin G. Seventh Biennial Student Substance Use Survey. Grades 7, 9 and 11. 1997-98. Sponsored by: California Department of Justice, Office of the Attorney General, Crime and Violence Prevention Center, California Department of Education, Department of Alcohol and Drug Programs, Department of Health Services, Office of AIDS.

30. Piecuch R, Leonard C, Cooper B, Sehring S. Outcome of extremely low bith weight infants (500 to 999 grams) over a 12 year period. Pediatrics 1997;100:633-639

31. Mertz, E., Grumbach K., MacIntosh L.; Coffman J. Geographic Distribution of Dentists in California, Dental Shortage Areas, 1998. Center for California Health Workforce Studies, University of California, San Francisco.

32. California Policy Seminar Brief. Asthma in California: laying the foundation for a Statewide strategy. 1998;10:1-4.

33. Chabra A., Chavez G., Adams E., Taylor D. Characteristics of children having multiple Medicaid-paid asthma hospitalizations. Maternal and Child Health Journal 1999.

34. Ikeda J., Mitchell M. Crawford P. Overweight Among Children in California, A Fact Sheet for Schools And Communities. Department of Nutritional Sciences, Cooperative Extension, University of California at Berkeley.